



*Better
Together*

Patient information

Immunoglobulin Replacement Therapy

Infection and Immunity

What is immunoglobulin?

Immunoglobulins are proteins found in the blood of all healthy individuals. Antibodies are immunoglobulins which become attached to harmful organisms (like viruses and bacteria) and protect against infection.

People who have a complete inability to make antibodies are almost always abnormally prone to infection.

People with a partial inability to make antibodies (they make antibodies to some organisms but not others) often have similar problems, though not always.

In either case, many of the missing antibodies can be replaced by giving immunoglobulin infusions.

The immunoglobulin used in these infusions is prepared using blood from normal human donors. There is no other way of obtaining it — it cannot be manufactured artificially.

What are the benefits of immunoglobulin infusions?

The aims of giving immunoglobulin treatment are:

- fewer infections
- less severe infections
- fewer complications of infection.

However, it cannot be said that immunoglobulin treatment gives complete protection from infection, and many patients will still need antibiotics from time to time (sometimes, even permanent, long-term antibiotics for prevention). Also, immunoglobulin treatment does not usually reverse any damage that has already been caused by previous infections.

Sometimes the case for starting immunoglobulin treatment is quite clear, especially if there is a complete inability to make antibodies. The case for treatment is often less clear in patients who have a partial inability to make antibodies - in these patients, immunoglobulin can be offered as a treatment if their history suggests they might benefit from it (generally, this means that they will have had significant problems in the past from unusually severe or unusually frequent infections).

What are the disadvantages of immunoglobulin infusions?

It is difficult to think of many effective treatments that cannot sometimes be harmful. Immunoglobulin is no different from other medical treatments in this respect.

Infection

Because immunoglobulin is made from human blood, the main risk is considered to be transmission of blood-borne infection. The infection risks which are most frequently considered are:

- hepatitis C: in the past, a number of patients have been infected with the hepatitis C virus from immunoglobulin infusions. However, since that time, new measures to prevent the transmission of viruses have been introduced into the manufacturing process, and it is felt that the risk of this infection is extremely low.
- HIV / AIDS: we are not aware of anyone ever having acquired this infection from an immunoglobulin infusion. The manufacturing process makes it very unlikely that this virus could survive in the final product.

- new variant CJD (human form of “mad cow” disease): the risk of this is considered to have been minimised by not using blood from British donors in the production of immunoglobulin.
- infections which we currently don’t know about, or new infection risks which might arise in the future.

Side-Effects

The commonest side-effects from immunoglobulin are similar to allergic reactions. These are quite common when patients are first started on treatment, and often become milder or disappear completely when treatment has been well-established. They are rarely severe or life-threatening and usually consist of mild symptoms that respond to simple treatment.

Life Style Changes

Starting immunoglobulin treatment is a significant step and will always affect the patient’s lifestyle in some way. Some find it more inconvenient than others. See below for a description of what the treatment involves.

How is immunoglobulin treatment given?

The treatment is always started in hospital. After patients are stabilised on treatment, many then have it at home. Whether to have treatment at home or continue to have it in hospital depends on a number of factors, including patient preference. This will all be discussed with you as and when appropriate.

There are two ways of giving the treatment:

1. Infusion into a vein in the hand or arm — this is **intravenous** treatment. Each infusion takes about two to four hours. Infusions are usually given every three weeks.
2. Infusions just under the skin — this is **subcutaneous** treatment. This only allows small amounts to be given at any one time, so it has to be done every week. However, this form of treatment is easier to give at home.

How long is the treatment continued for?

In many cases, especially for patients with complete antibody deficiency, once immunoglobulin treatment is started, it is never stopped.

However, there are some situations where, after discussion with you, we will advise stopping immunoglobulin, at least temporarily.

These include:

- if you appear to be getting little benefit from it
- if there is good reason to re-assess the need for it. This is particularly important in patients with partial antibody deficiency, where the need for immunoglobulin is sometimes not clear-cut (as discussed above). Sometimes, there might be improvements in laboratory tests, which would allow a more accurate assessment of your own immune system than was possible before you started immunoglobulin treatment. Sometimes there might be improvements in vaccines that could stimulate your own immune system to produce antibodies. Sometimes there might be a change of medical opinion on the use of immunoglobulin treatment. These are all possible.

- if you decide that you want to stop the treatment for reasons of your own.

You need to be aware of the above information so that you are not surprised or disappointed if we suggest stopping immunoglobulin treatment at some stage to allow a re-assessment.

Should I have immunoglobulin treatment?

By the time you have been given this sheet to read, there will already have been a medical opinion that it would at least be reasonable for the treatment to be offered to you. However, only you can make the decision to have the treatment or not.

In making your decision, we ask you to consider carefully all of the information on this sheet and all the information we have given you about your particular medical circumstances. It is essential that you discuss any questions or areas of doubt with us.

If you decide to have immunoglobulin treatment, we will ask you to sign a consent form for the treatment to indicate that you are happy that you have been given enough information. Before signing this, you should be satisfied that we have answered any questions you want to ask.

Further information

Further information can be obtained by contacting the Immunology Clinical Nurse Specialist, Craig Simon:

Tel: 0151 706 2000 ext. 4359, or bleep 4455

Text phone number: 18001 0151 706 2000 ext. 4359, or bleep 4455

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Related Patient Information: Subcutaneous Immunoglobulin Therapy and Home Treatment.

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